



## **FAMILY “TOOLS OF ENGAGEMENT” BEST PRACTICE 4**

### **BEST PRACTICE 4**

*Coach families, friends, and caregivers in the principles, techniques, and value of partnering with the patient and his or her inter-disciplinary health care team.*

### **HOW DO YOU ACHIEVE THIS BEST PRACTICE?**

- 1) Teach families and caregivers about the defining attributes of partnerships, including:
  - a) A genuine and trusting relationship
  - b) Honest and open communication and listening
  - c) Praise and encouragement
  - d) Reciprocity
  - e) Empathy
  - f) Respect for each other’s expertise
  - g) Working together with negotiation of goals, plans and boundaries
  - h) Participation and involvement
  - i) Support and advocacy
  - j) Willingness to share information
  - k) Commitment to “enable choice and equity” (Bidmead & Crowley, p.206)
  
- 2) Teach families and caregivers communication skills that allow them to effectively partner with the health care team and advocate for the patient. These skills include the ability to:
  - a) Negotiate
  - b) Share decisions
  - c) Collectively solve problems
  - d) Establish goals
  - e) Take action
  - f) Identify strengths and weaknesses
  - g) Clarify roles and responsibilities
  - h) Evaluate progress (refer to “New Health Partnerships” under Tools)

- 3) Help caregivers focus on coping skills and resources, including:
  - a) How to communicate with the patient
  - b) Where to find support services
  - c) How to be an advocate for the patient
  - d) How to recognize caregiver stress
  - e) The Importance of caring for self
  - f) How to develop individualized strategies to reduce stress
  
- 4) Teach families and caregivers how to optimize care-giving when they can't be there, including how to:
  - a) Assess the multi-faceted needs of the patient, from health care to living assistance
  - b) Develop a plan of care
  - c) Provide on-going support and education
  - d) Communicate with the healthcare team
  - e) Seek help from neighbors and friends
  - f) Use community resources for care
  - g) Seek out technologies that connect families to the patient and to health care providers (see Technologies under Tools)
  - h) Organize transportation, meals, recreation, etc.
  - i) Mobilize resources during an emergency
  - j) Choose professionals that specialize in Geriatrics
  - k) Manage documents, insurance, and legal matters
  - l) Care for themselves
  
- 5) Guide caregivers in partnering effectively with senior housing, home health care, assisted living, and nursing homes to ensure communication across all settings.

## FAMILY ENGAGEMENT BEST PRACTICE 4: TOOLS AND RESOURCES

Web-Based Tools and Resources	
<b>“Ask the Doctor”</b>	National Kidney Foundation <a href="http://www.kidney.org/patients/Dr_SpryQ&amp;A.cfm">http://www.kidney.org/patients/Dr_SpryQ&amp;A.cfm</a>
<b>Caregiving/Long-Distance Caregiving Resources</b>	AARP <a href="http://assets.aarp.org/external_sites/caregiving/planAhead/long_distance_issues.html">http://assets.aarp.org/external_sites/caregiving/planAhead/long_distance_issues.html</a>  Long Distance Caregiving <a href="http://www.longdistancecaregiving.com/">http://www.longdistancecaregiving.com/</a>  National Family Caregiver Association <a href="http://www.nfcares.org/caregiving_resources">http://www.nfcares.org/caregiving_resources</a>  National Kidney Foundation <a href="http://www.kidney.org/patients/pfc/caregiver.cfm">http://www.kidney.org/patients/pfc/caregiver.cfm</a>
<b>Decreasing Patient-Provider Conflicts</b>	National Forum of ESRD Networks <a href="http://esrdnetworks.org/special-projects/copy_of_decreasing-patient-provider-conflict-dpc">http://esrdnetworks.org/special-projects/copy_of_decreasing-patient-provider-conflict-dpc</a>
<b>Emergency Patient Resources</b>	Kidney Community Emergency Response Coalition <a href="http://www.kcercoalition.com/resources.htm">http://www.kcercoalition.com/resources.htm</a>
<b>Health Literacy Information Translations</b>	Ohio Health/Nationwide Children’s Hospital <a href="http://www.healthinfotranslations.org/">http://www.healthinfotranslations.org/</a>
<b>Partnering in Self-Management: A Toolkit for Clinicians</b>	New Health Partnerships <a href="http://www.newhealthpartnerships.org">http://www.newhealthpartnerships.org</a>
<b>Partners in Care</b>	Dialysis Patient Citizens <a href="http://www.dialysispatients.org/partners-in-care">http://www.dialysispatients.org/partners-in-care</a>
<b>SeniorHealth Videos</b>	National Institutes of Health List of videos - <a href="http://nihseniorhealth.gov/videolist.html">http://nihseniorhealth.gov/videolist.html</a>
<b>Support/Education Network</b>	Renal Support Network <a href="http://www.rsnhope.com">www.rsnhope.com</a>
<b>Your Dialysis Care Team</b>	National Kidney Foundation <a href="http://www.kidney.org/atoz/content/dialcareteam.cfm">http://www.kidney.org/atoz/content/dialcareteam.cfm</a>

Printed Tools and Resources	
<b>Caregiving/Long-Distance Caregiving Resources</b>	<p>Caring from a Distance <a href="http://www.cfad.org/">http://www.cfad.org/</a></p> <p>Family Caregiver Alliance <a href="http://www.caregiver.org/caregiver/jsp/content/pdfs/op_2003_long_distance_handbook.pdf">http://www.caregiver.org/caregiver/jsp/content/pdfs/op_2003_long_distance_handbook.pdf</a></p> <p>National Alliance for Caregiving <a href="http://www.nahu.org/consumer/MMISYCHiringIndependentCare07.pdf">http://www.nahu.org/consumer/MMISYCHiringIndependentCare07.pdf</a></p> <p>National Institute on Aging <a href="http://www.nia.nih.gov/So_Far_Away_FINAL707.pdf">http://www.nia.nih.gov/So_Far_Away_FINAL707.pdf</a></p> <p>National Kidney Foundation <a href="#">Long-term Care Residence Chronic Kidney Disease Checklist</a></p> <p>Senior Housing Net <a href="http://www.seniorhousingnet.com/care-selection/glossary.aspx">http://www.seniorhousingnet.com/care-selection/glossary.aspx</a></p> <p>University of Missouri – Kansas City <a href="http://cas.umkc.edu/casww/ldcargvr.htm">http://cas.umkc.edu/casww/ldcargvr.htm</a></p>
Telephonic, Audio, & Live Resources	
<b>A Conversation with a Nurse (Podcast)</b>	<p>Renal Support Network This program describes one nurse’s approach to taking time to listen to her patients, answer questions, resolve issues, and explain treatments. <a href="#">Play Now</a></p>
<b>Patient Lifestyle Meetings</b>	<p>Renal Support Network Hopeline - Call 1-800-579-1970</p>
<b>People Like Us: Coffee House Conversations</b> (Live, telephonic and/or pre-recorded web-based)	<p>National Kidney Foundation <a href="http://www.kidney.org/coffeehouse/">www.kidney.org/coffeehouse/</a></p>
<b>Planning for Emergencies: A Guide for People with Chronic Kidney Disease</b>	<p>National Kidney Foundation Call 1-800-622-9010</p>
Technologies to Connect Families to Patients and Providers	
<b>Blogs/Forums/Social Networks</b>	<p>DaVita, Inc. <a href="http://www.davita.com/forum/">http://www.davita.com/forum/</a> <a href="http://www.davita.com/blogs/">http://www.davita.com/blogs/</a> <a href="http://www.kidneypostings.com/">http://www.kidneypostings.com/</a> <a href="http://kidneypostings.davitablogs.com/?p=99">http://kidneypostings.davitablogs.com/?p=99</a> (Caregiver Support)</p>

<p><b>eCommunication Technologies</b></p>	<p>MSN - <a href="http://windowlive.com/desktop/messenger">http://windowlive.com/desktop/messenger</a></p> <p>Skype - <a href="http://www.skype.com/intl/en-us/home">http://www.skype.com/intl/en-us/home</a></p> <ul style="list-style-type: none"> <li>BDP: UCSF partners with Skype to connect patients with family and friends - <a href="http://news.ucsf.edu/releases/UCSF-partners-with-Skype-to-connect-patients-with-family-friends/">http://news.ucsf.edu/releases/UCSF-partners-with-Skype-to-connect-patients-with-family-friends/</a></li> </ul> <p>Vizuphone - <a href="http://www.vizuphone.com/">http://www.vizuphone.com/</a></p> <ul style="list-style-type: none"> <li>Best Demonstrated Practice (BDP), UC Davis Medical Center: Connecting pediatric patients and their families - <a href="http://www.ucdmc.ucdavis.edu/cht/services/telemedicine/family.html">http://www.ucdmc.ucdavis.edu/cht/services/telemedicine/family.html</a></li> </ul> <p>Yahoo - <a href="http://messenger.yahoo.com/">http://messenger.yahoo.com/</a></p>
<p><b>Facebook</b></p>	<p>Davita on Facebook <a href="http://www.facebook.com/davitakidneycare?utm_source=davidadotcom&amp;utm_medium=socialmedia_textlink&amp;utm_campaign=facebook_fan">http://www.facebook.com/davitakidneycare?utm_source=davidadotcom&amp;utm_medium=socialmedia_textlink&amp;utm_campaign=facebook_fan</a></p> <p>People Like Us on Facebook - National Kidney Foundation <a href="http://www.facebook.com/home.php?#!/group.php?gid=417996565113">http://www.facebook.com/home.php?#!/group.php?gid=417996565113</a></p> <p>Renal Support Network Facebook Page <a href="http://www.facebook.com/pages/Renal-Support-Network/174580037735?ref=ts">http://www.facebook.com/pages/Renal-Support-Network/174580037735?ref=ts</a></p>
<p><b>Home Dialysis Information</b></p>	<p><a href="http://www.davita.com/home/">http://www.davita.com/home/</a></p> <p><a href="http://www.ultracare-dialysis.com/engine/renderpage.asp?pid=s0015">http://www.ultracare-dialysis.com/engine/renderpage.asp?pid=s0015</a></p>
<p><b>Patient Travel Services and Resources</b></p>	<p><a href="http://www.dialysisfinder.com/">http://www.dialysisfinder.com/</a></p> <p><a href="http://www.ultracare-dialysis.com/engine/renderpage.asp?pid=s0018">http://www.ultracare-dialysis.com/engine/renderpage.asp?pid=s0018</a></p> <p><a href="http://www.davita.com/dialysis-travel/">http://www.davita.com/dialysis-travel/</a></p>
<p><b>Personal and Private Websites/Blogs for People and Families with Health Care Challenges</b></p>	<p>Caringbridge <a href="http://www.caringbridge.org">www.caringbridge.org</a></p> <p>CarePages <a href="http://www.carepages.com/search?search%5Bterms%5D=kidney">http://www.carepages.com/search?search%5Bterms%5D=kidney</a></p>

<p><b>Twitter</b></p>	<p>DaVita on Twitter  <a href="http://twitter.com/davita?utm_source=davitadotcom&amp;utm_medium=socialmedia_textlink&amp;utm_campaign=twitter_follow">http://twitter.com/davita?utm_source=davitadotcom&amp;utm_medium=socialmedia_textlink&amp;utm_campaign=twitter_follow</a></p> <p>People Like Us on Twitter - National Kidney Foundation  <a href="http://twitter.com/NKFPeopleLikeUs">http://twitter.com/NKFPeopleLikeUs</a></p>
<p><b>Use of Personal Health Record (PHR) for Connecting Families w/ Patient's Health Information</b></p>	<p>Benefits of PHR  <a href="http://healthit.ahrq.gov/portal/server.pt?CommunityID=666&amp;spaceID=399&amp;parentname=&amp;control=SetCommunity&amp;parentid=&amp;PageID=0&amp;space=CommunityPage&amp;in_tx_query=Benefits+of+PHRs&amp;Submit.x=19&amp;Submit.y=10">http://healthit.ahrq.gov/portal/server.pt?CommunityID=666&amp;spaceID=399&amp;parentname=&amp;control=SetCommunity&amp;parentid=&amp;PageID=0&amp;space=CommunityPage&amp;in_tx_query=Benefits+of+PHRs&amp;Submit.x=19&amp;Submit.y=10</a></p> <ul style="list-style-type: none"> <li>• BDP: My PHRs help me care for two elderly family members -  <a href="http://www.myphr.com/index.php/phr_success_stories/article/2196/">http://www.myphr.com/index.php/phr_success_stories/article/2196/</a></li> </ul>
<p><b>Supporting Literature</b></p>	
<p>Bidmead C and Cowle, S. <b>A concept analysis of partnership with clients.</b> <i>J Community Pract.</i> 2005 78(6):203-208. <a href="http://www.ncbi.nlm.nih.gov/pubmed/15984559">http://www.ncbi.nlm.nih.gov/pubmed/15984559</a></p>	
<p>Wiggins M. <b>The partnership care delivery model.</b> <i>J Nurs Adm.</i> 2006 36(7/8):341-345.  <a href="http://journals.lww.com/ionajournal/Abstract/2006/07000/The_Partnership_Care_Delivery_Model.2.aspx">http://journals.lww.com/ionajournal/Abstract/2006/07000/The_Partnership_Care_Delivery_Model.2.aspx</a></p>	
<p>Wiggins M. <b>The partnership care delivery model: An examination of the core concept and the need for a new model of care.</b> <i>J Nurs Manag.</i> 2008 16:629-638.  <a href="http://www3.interscience.wiley.com/journal/120087738/abstract">http://www3.interscience.wiley.com/journal/120087738/abstract</a></p>	
<p>Wooton R, et al. <b>Home telehealth: Connecting care within the community.</b> 2006.  <a href="http://books.google.com/books?hl=en&amp;lr=&amp;id=ccRC6ykyKBYC&amp;oi=fnd&amp;pg=PR9&amp;dq=connecting+patient+families&amp;ots=WyM0PFXWgl&amp;sig=pvgTIMfYyIfSkzZ1H0Q_skPQjIQ#v=onepage&amp;q&amp;f=false">http://books.google.com/books?hl=en&amp;lr=&amp;id=ccRC6ykyKBYC&amp;oi=fnd&amp;pg=PR9&amp;dq=connecting+patient+families&amp;ots=WyM0PFXWgl&amp;sig=pvgTIMfYyIfSkzZ1H0Q_skPQjIQ#v=onepage&amp;q&amp;f=false</a> (Book available to purchase from site.)</p>	

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